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Understanding and Supporting Adults with Fetal Alcohol Spectrum Disorder - Strategies for Health Professionals: an Opinion Piece

Fetal Alcohol Spectrum Disorder (FASD) is a non-diagnostic umbrella term used to describe the spectrum of lifelong physical, mental and intellectual disabilities that can result from prenatal exposure to alcohol. Fetal Alcohol Spectrum Disorder is preventable when pregnant women abstain from drinking any type or amount of alcohol at any time during pregnancy. One in 100 children worldwide are affected. Prompt diagnosis and treatment referrals for infants and children improve functionality. Yet, conditions related to fetal alcohol exposure frequently remain unrecognized and untreated. Adults with both diagnosed and hidden Fetal Alcohol Spectrum Disorder experience significant cognitive, behavioral and executive functioning deficits. Co-morbid physical and psychiatric disorders are common. This editorial provides health professionals with information to understand and support adults with Fetal Alcohol Spectrum Disorder. Specific strategies related to initiating referrals to community services, communicating intentionally and responding positively to behavioral challenges are discussed.

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ABSTRACT

Fetal alcohol spectrum disorder (FASD) is a non-diagnostic umbrella term used to describe the spectrum of lifelong physical, mental, and intellectual disabilities that can result from prenatal exposure to alcohol. FASD is preventable when pregnant women abstain from drinking any type or amount of alcohol at any time during pregnancy. One in 100 children worldwide are affected. Prompt diagnosis and treatment referrals for infants and children improve functionality. Yet, conditions related to fetal alcohol exposure frequently remain unrecognized and untreated. Adults with both diagnosed and hidden FASD experience significant cognitive, behavioral, and executive functioning deficits. Co-morbid physical and psychiatric disorders are common. This editorial presents health professionals with information to understand and support adults with FASD. Specific strategies related to initiating referrals to community services, communicating intentionally, and responding positively to behavioral challenges are discussed.

Key Words: Fetal Alcohol Spectrum Disorder, FASD, adults with FASD, supporting adults with FASD

INTRODUCTION

Fetal alcohol spectrum disorder (FASD) is an umbrella term used to describe the myriad of lifelong physical, mental, and intellectual disabilities that result from exposure to alcohol during pregnancy.^{1,2} FASD is not a clinical diagnosis, however, and includes within its spectrum the following diagnoses: fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), alcohol related birth defects (ARBD), alcohol related neuro-developmental disorder (ARND), and neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE).³

Out of all the substances of abuse, alcohol has the most serious effects on a developing fetus, and FASD is considered the leading cause of preventable developmental and cognitive disabilities.^{3,4} In the United States, 1 in 10 expectant mothers reported consuming alcohol in the past 30 days, and 1 in 33 reported binge drinking.⁵ In South Africa, where the highest rates of FASD occur in the world, more than 20% of women reported drinking alcohol during their pregnancies.⁶

In 2010, the World Health Organization (WHO) endorsed a global strategy to prevent the use of alcohol during pregnancy.⁷ Following the example set in Scandinavian countries, the Chief Medical Officers for the United Kingdom (UK), the National Health and Medical Council of Australia, and the American Academy of Pediatrics in the United States (US) have all asserted that there is no safe time, no safe amount, and no safe type of alcohol during pregnancy.^{3,8-10}

However, despite continued educational efforts advising against drinking during pregnancy, expectant mothers continue to imbibe, which results in negative outcomes for the affected children.¹¹⁻¹³ Further, many of these children go undiagnosed, resulting in lifelong impairments without recognition of needed care and treatment.¹⁴

FASD has emerged globally as a significant burden on economic, social, and public health systems.¹⁵ At the systems level, direct costs include high use of health care, law enforcement, special education, and care services.¹⁵ At the individual level, indirect costs to people living with FASD include loss of productivity, increased morbidity, and early mortality.¹⁵ One in every 100 children worldwide are born with FASD.¹⁶ The prevalence of FASD among special populations, such as Aboriginal peoples, children in foster care, and those who are incarcerated or receiving psychiatric treatment has been estimated to be even greater, ranging from 5 to 68 times higher than the general population.¹⁶

The effects of FASD influence how people function for the rest of their lives. Those affected frequently experience co-morbid conditions. For example, lifelong impairments related to language, auditory, visual, behavioral, and mental problems are common in 50% to 91% of the FASD population.¹⁷ Physical defects, adaptive functioning deficits, and congenital anomalies, such as malformations and dysplasia of the cardiac, skeletal, renal, ocular, auditory and other systems, are common.¹⁵ Approximately 90% have mental health concerns, and in adulthood, one of the most severe characteristics of FASD is the presentation of a major mental health diagnosis.¹⁸⁻²⁰

Health professionals from a variety of different settings can expect to encounter adults with FASD in their practice. Existing information for preventing FASD, supporting women who consume alcohol during their pregnancies, and interventions for infants and children with FASD is widely available. However, the condition may go unrecognized and untreated in many adults. Increasing understanding of FASD among all members of health care teams can make an important difference in initiating appropriate support. Geared to a multidisciplinary audience, this editorial presents practical and supportive strategies health care providers can readily implement.

UNDERSTANDING FASD

FASD in Children

Diagnosing conditions along the FASD spectrum, which include FAS, pFAS, ARBD, ARND and ND-PAE, is a complex process that usually requires physical and neurodevelopmental assessments from a multidisciplinary team.¹⁴ Agreement on a universal diagnostic system for FASD is lacking among investigators in the field. In infants, it is generally accepted that in addition to indications of growth deficiencies and developmental delays, the following are expected: documentation of significant prenatal alcohol use, smaller than normal head circumference, short palpebral fissures (small eye openings), smooth philtrum (rather than the usual raised vertical groove between the base of the nose and the border of the upper lip), and thin vermilion border of the upper lip.²¹ It is important to note that many infants and children with FASD manifest the characteristic developmental delays yet lack the growth impairments or clearly abnormal facial features expected.²²

Children who present with recognizable symptoms of FASD and who are promptly diagnosed and referred to social services, special education programs, and specialized medical care, can improve their chances of functioning well in life.²³ Unfortunately, studies regarding the prevalence rates of diagnosis indicate that only 1% to 10% of individuals with FAS are identified and receive

a diagnosis, and those with pFAS and ARND, diagnoses are made even less frequently, leading to a large proportion of affected individuals without support of any kind.²⁴⁻²⁶

Many children with FASD have IQ scores of less than 70, difficulties with communication, poor social skills, and problems with daily living skills.^{1,25,27,28} Children who have characteristics of FASD but who achieve IQ scores greater than 70 are less likely to be recognized as needing support, putting them at high risk for delinquency, school failure, and other negative life outcomes.^{20,29}

FASD in Adults

As children age, diagnosing FASD becomes increasingly more complicated. The risk of head trauma, violence, and drug and alcohol abuse increases, and older children and adolescents can lose the abnormal facial features present at birth.³⁰ Further, validating documents from childhood indicating growth restrictions, facial features, and records confirming maternal drinking may be unobtainable. For children who were adopted or whose mothers are unwilling to disclose alcohol use, this information is often difficult for affected individuals to acquire.

Adolescents and adults with unrecognized FASD can establish patterns of inappropriate behavior, emotional problems, poor school functioning, and negative family interactions.³¹ Unrecognized FASD is often seen in high-risk settings, such as psychiatric hospitals, the child welfare system, and juvenile detention and correctional facilities.³¹ People who do not meet diagnostic criteria for a disorder on the FASD spectrum yet still present with cognitive and behavioral deficits are often termed as "hidden," and it is estimated that these manifestations are 6 to 8 times more common than FAS.³²

The deficits that people living with both diagnosed and hidden FASD experience are profound. Executive functioning (higher level cognitive abilities, such as thinking abstractly, planning ahead, solving problems, and being flexible), social skills, memory, learning, frustration tolerance, ability to pay attention, and activity/hyperactivity levels are all affected to varying degrees.^{26,29,33,34} These deficits prevent individuals with FASD from leading successful, independent lives, delay academic achievement, increase the need for supported living, and may put the individual at risk for poverty, abuse, and violence.^{27,29} Individuals with FASD are at a higher risk than the general population to come into contact with the law.^{30,35,36}

SUPPORTING PEOPLE WITH FASD

People with FASD use health, educational, and social services at rates exceeding both the general population and those with chronic illnesses.³⁷ They have 3 times as many hospitalizations, oftentimes for mental health concerns, such as depression, mood disorders, anxiety disorders, attention deficit hyperactivity disorder (ADHD), and substance misuse.^{28,37,38} Physical concerns, such as vision and hearing loss, are also common.¹⁷ Additionally, rates of rheumatoid arthritis, celiac disease, lupus, early onset dementia, and chronic ear infections are also higher than the general population.³⁷

Given the range of co-occurring mental and physical disorders that cause people with FASD to seek medical help, health practitioners can expect to encounter adults with diagnosed and hidden FASD in most clinical areas. Yet, many health professionals are not able to identify that they ever worked with a patient/client with FASD or suspected FASD.³⁸ Many feel ill-prepared to work with this group of people and may misinterpret behaviors as "willful" or defiant, rather than manifestations of the cognitive and behavioral deficits associated with FASD.³⁹

When health professionals are unaware that people with FASD need enduring and long-term support, they may discontinue services when they observe progress. However, this progress may not be maintained without continued contact and guidance.^{30,32} Care providers may attempt to teach patients/clients new skills without consideration for their problems with comprehension, memory, and processing new information.⁴⁰ Even professionals in specialized mental health care areas expressed difficulty differentiating among symptoms of psychiatric illness, brain injury, and FASD.⁴¹ In the following section, strategies drawn from existing literature as well as our own experiences that can help practitioners effectively support adults with diagnosed and hidden FASD are presented.

STRATEGIES FOR HEALTH PROFESSIONALS

It is important to emphasize that although people with FASD can be expected to face similar challenges, each individual will present with a wide range of cognitive, behavioral, and executive functioning deficits. Fetal development can be affected by alcohol in differing amounts and at any stage. As a teratogenic substance, alcohol crosses the placenta with ease and, depending upon sensitivities of the mother and child, causes dissimilar effects, depending on the exposure.⁴² Functional assessments in which specific deficits and capabilities are identified yield important information that professionals can use to create intervention plans tailored to individuals' needs.^{26,27,29} Bearing in mind the diverse range of FASD clinical presentations, the strategies suggested below must be adapted to the unique needs of individual patients/clients.

Initiate Referrals to Community Services

Long-term support. For people with FASD, connections with community services can make a crucial difference in their ability to cope and succeed with the challenges of everyday life.⁴⁰ At a foundational level, health practitioners can initiate referrals that ensure their patients/clients have access to long-term support from employment services, vocational rehabilitation and social services and, when necessary, mental health care, Aboriginal support groups, substance abuse programs, and correction facilities programs.³²

Practical assistance that health professionals can offer include accompanying people to appointments with the services they need; making follow-up appointments; and noting these appointments on calendars, day-timers, or Smartphones. One can suggest scheduling appointments on the same day and time each week or month. People may find it easier to remember to attend an appointment every Monday afternoon at 2 PM, than if the appointments were scheduled at different times each week.

Diagnosis

When feasible, family members should be encouraged to participate in programs the community services offer. One can invite family members, friends and other advocates to gather data that may assist clinicians in diagnosing a disorder on the FASD spectrum, such as indications of prenatal exposure to alcohol, infant facial characteristics associated with FASD, growth deficiencies, developmental delays and special education needs, assessment, and supports at school. A confirmed FASD diagnosis will help patients/clients receive essential long-term support.

Social Support. Community service programs may host support groups and social activities that people with FASD can benefit from. Those affected by FASD have difficulty in social situations and often do not have reciprocal friendships or peer relationships. They may view a casual acquaintance as a true friend. Feelings of inadequacy and social disconnection can be present. Many feel as though they do not fit in in social situations yet are at a loss as to how to behave appropriately. Events guided by trained facilitators can help people learn more about appropriate social interactions.

Because adults with FASD likely fell behind their peer group growing up, they may have immature and under developed social skills. They may have been repeatedly taken advantage of, teased, and bullied. As a result, in adolescence and adulthood, they may turn to negative peer groups in order to experience a sense of belonging. When these groups are involved in criminal activities, those with FASD may be goaded into committing crimes and then scapegoated when caught. Because of their lack of adequate supports and strong desire to be accepted by peers, they often do not recognize they are being used.

Although community service agencies and programs cannot be expected to meet all the varied needs for social support that adults with FASD have, they may be able to provide alternatives to negative peer group influences. Sessions with counsellors can help people search for ways to find positive activities and relationships that are genuine and reciprocal.

In our view, initiating referrals that result in establishing a network of community services and supports for people, especially before they are discharged from a care facility, will equip them to continue working on the skills they learned and may help them feel more connected to their communities. The support networks associated with community services will provide a foundation for people to stay well and possibly avoid future physical and mental health crises.

Communicate Intentionally -- Comprehension

When people with FASD have difficulty hearing words, processing information, expressing themselves, interpreting social cues, paying attention, and remembering points made during conversations, health professionals are not able to provide them with information relevant to their care. In some instances, rather than stating they do not understand, people with FASD may comment superficially, smile, and nod an affirmation.

Therefore, in order to verify comprehension, consider asking patients/clients at different times to reiterate the information they have heard in their own words. Key information can be repeated a number of times over the course of multiple interactions to assist in information retention. Limit the amount of information given to the patient at any one time.

Communicate Intentionally -- Language

Use simple nonmedical terms and concrete language whenever possible. Vague terms, such as “maybe” and “sometimes if” can be confusing. Abstract questions may elicit inaccurate responses. For example, in response to the question: “Do you feel alone?” a response might be “No” because the patient/client is currently sitting with the professional. This response indicates a concrete rather than abstract understanding of the word “alone.”

Communicate Intentionally -- Stimulation

People with FASD often experience sensory overload and overstimulation. One can help patients/clients recognize triggers that cause them to feel agitated and explore ways they can develop coping skills. Florescent lights; computer screens, uncomfortable clothing, and overly crowded spaces and background noises, such as coffee pots, ticking clocks, and humidifiers, can be very distracting to people with FASD; therefore, it is better for these patients to ensure conversations take place in quiet spaces and away from any glaring lights. One can role model strategies for coping, such as dimming lights and appropriate ways of sharing feelings of frustration.

Perhaps most importantly, patients/clients should be guided towards developing realistic plans for dealing with feeling overwhelmed. Realistic plans are especially important in social situations. People need to know their limits, who they can call, and even where they can go to manage their distress. Writing down the plan and inviting patients/clients to share it with professionals and family members is useful.

Communicate Intentionally -- Emotions

One needs to recognize when people are struggling with identifying emotions. Finding the right words to describe feelings can be hard. Charts and pictures can be used as illustrations. Similarly, providing sufficient time for people to share their concerns is important.

Respond Positively to Behavioral Challenges

The cognitive impairments associated with FASD can heighten impulsivity and decrease cause-and-effect reasoning. Those who are affected may take things that do not belong to them, interrupt others, behave inappropriately, and appear as though they do not take responsibility for their actions. They may also have trouble with time management. For example, a patient/client may arrive late for a 1 PM appointment because s/he left home at 1 PM, forgetting to allow time for travel. Problems with money management and coping with change are also common.

In these instances, rather than assuming people are deliberately defying social conventions or being thoughtless, it is important to remember that FASD affects brain development in utero. People with this condition have not been born with the same capacity to reason as the general population. Finding ways to direct people toward that which needs to be done and how to behave, rather than focusing on that which does not need to be done or how not to behave can be effective. Providing too many instructions or too many "should nots" can feel overwhelming, resulting in people simply not committing the information to long-term memory.

Problem behavior cannot be ignored and negative consequences must be imposed when necessary. In order to establish connections with the behavior, these consequences should be imposed immediately and consistently by all those involved in providing support. On the other hand, frequent, immediate, and consistent positive feedback that recognizes appropriate behavior should also be offered. Predictable structured routines can help prevent behavioral challenges from developing into problem behaviors.

CONCLUSION

In summary, this editorial presented an overview of FASD, explaining how the term refers to a spectrum of devastating disabilities caused by prenatal exposure to alcohol. People with FASD live with the physical, mental, and behavioral disabilities all their lives. Consequently, the support and care they need must also continue throughout their lives. When infants and children are diagnosed early and connected with specialized social, educational, and medical programs, they are better equipped to deal with the ongoing challenges they face. However, for a significant number of affected people, deficits related to FASD go unrecognized, undiagnosed, and unsupported. The many physical and mental co-morbid conditions they struggle to cope with often bring them into contact with health professionals, many of whom have only a limited understanding of FASD. Effective strategies that practitioners can implement include initiating referrals to community services. For those adults whose FASD is unrecognized or hidden, connections to agencies and programs that will provide the long-term support they need can make a crucial difference. These connections can help people find clinicians who are able to confirm a diagnosis on the FASD spectrum.

When communicating with people with FASD, another important strategy is to intentionally consider their level of comprehension. Rather than assuming that smiling, nodding, and superficial responses indicate understanding, asking patients/clients to re-iterate any instructions in their own words is a more accurate measure of comprehension. Similarly, using concrete rather than abstract language, minimizing environmental stimulation, and providing extra time for expressing emotions are worthwhile.

Finally, strategies that help practitioners respond positively to behavioral challenges, such as offering positive feedback and giving clear direction about the actions people should take are helpful. We call for health professionals to continue developing an

understanding of the disabilities associated with FASD in adulthood and the kinds of supportive strategies that can begin to make life easier for the many people affected.

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